



NURSING: DEATH AND DYING IN A PEDIATRIC AND NEONATAL INTENSIVE CARE UNIT

ENFERMAGEM: A MORTE E O MORRER EM UNIDADE DE TERAPIA INTENSIVA PEDIÁTRICA E NEONATAL

ENFERMERÍA: LA MUERTE Y EL MORIR EN UNA UNIDAD DE CUIDADOS INTENSIVOS NEONATAL Y PEDIÁTRICA

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ABSTRACT

Objective: to analyze how the nursing staff of a Pediatric and Neonatal Intensive Care Unit lives the death and dying of patients. **Method:** a qualitative, descriptive and exploratory study. It was formulated a guiding question << *How is for you to experience the death and dying of children and neonates hospitalized in an ICU PN?* >> The construction of information was carried out through interviews recorded in March 2012, with 20 nurses, after approval of the research project Ethics Committee of Research, CAAE nº 01224012.8.0000.5350. **Results:** a category of analysis and, from that, three subcategories: << *Experiencing death: the broken bond and sense of loss* >>, << *The favorable evolution and the unexpected death* >> and << *The professional before the family* >>. **Conclusion:** the need for a greater investment, personal and institutional, to minimize the suffering of workers living with such a situation. **Descriptors:** Death; Dying; ICU; Newborns; Children.

RESUMO

Objetivo: analisar como a equipe de Enfermagem de uma Unidade de Terapia Intensiva Pediátrica e Neonatal vive a morte e o morrer de pacientes. **Método:** estudo qualitativo, descritivo e exploratório. Foi formulada a questão norteadora << *Como é para você vivenciar a morte e o morrer de crianças e neonatos internados em uma UTI PN?* >> A construção das informações foi realizada por meio de entrevistas gravadas no mês de março de 2012, com 20 profissionais de enfermagem, após a aprovação do projeto de pesquisa Comitê de Ética em Pesquisa, CAAE nº 01224012.8.0000.5350. **Resultados:** uma categoria de análise e dessa, três subcategorias: << *Vivenciando a morte: o vínculo quebrado e o sentimento de perda* >>, << *A evolução favorável e a morte inesperada* >>, e << *O profissional diante dos familiares* >>. **Conclusão:** necessidade de maiores investimentos, pessoais e institucionais, visando minimizar o sofrimento dos trabalhadores que convivem com tal situação. **Descritores:** Morte; Morrer; UTI; Neonatos; Crianças.

RESUMEN

Objetivo: analizar cómo el personal de Enfermería de una Unidad de Cuidados Intensivos Pediátrica y Neonatal vive la muerte y el morir de los pacientes. **Método:** un estudio cualitativo, descriptivo y exploratorio. Fue formulada la pregunta guía << *¿Cómo es para usted experimentar la muerte y el morir de niños y neonatos hospitalizados en una UCI PN?* >> La construcción de las informaciones se realizó a través de entrevistas grabadas en marzo de 2012 con 20 enfermeras, después de la aprobación del proyecto de investigación del Comité de Ética de Investigación, CAAE nº 01224012.8.0000.5350. **Resultados:** una categoría de análisis y, de esta, tres subcategorías: << *Experimentando la muerte: el vínculo roto y el sentimiento de pérdida* >>, << *La evolución favorable y la muerte inesperada* >> y << *El profesional frente la familia* >>. **Conclusión:** la necesidad de mayores inversiones, personales e institucionales, para reducir al mínimo el sufrimiento de los trabajadores que viven con esa situación. **Descritores:** Muerte; Morir; UCI; Recién Nacidos; Niños.

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INTRODUCTION

The death comes from life. This is a reality for everyone and that is a fact. However, and in today's society, experiencing death has made this much more present for professionals in the field of health in their daily do, live with the "process of death and dying", *death* being interpreted by the author as a definitive interruption of life and dying as the time that elapses between the time when the disease becomes irreversible even when the individual fails to respond to any therapeutic measure progressing to death.¹

The ways of seeing and experiencing the processes of health and disease, life and death, as well as spaces of attention to those in a situation of health worsening and risk of death and dying, has been changing in societies in general and taken forms, several before, now somewhat more hegemonic. Actually, the great majorities of people are born and die in hospital spaces.

Among the units of hospital care, it is in the ICUs, where the highest rates of hospital mortality, as these are fitted with technology to care for seriously and recoverable patients, even when used at their full potential in an attempt to "defeat death" many will be defeated by it.²

In the social context and as a natural process of life it is accepted with certain naturalness, when elderly people progress to death. However, when it comes to coping with the process of death and dying of newborn (NB) and children, the subject ceases to be natural and become complex, and even in constituting professional healthcare, and more we study, we think and try to understand these events, do not learn to deal with such situations.

In seeking care it needs to cope with death, with family and with one's own self, as a human and professional who lives and faces before death in the routine of his doing.³ We understand that it is a precondition for professionals to be prepared to receive and care for patients and their families during hospitalization. However, and more than nurses and nursing staff can be prepared, the fact of experiencing the death of a patient, especially when are children and infants, can cause reactions and the most diverse behaviors.

Therefore, and considering that, due to the form of organization of the work process in hospital units is nursing the professional category that first copes and realizes the death of hospitalized patients is that we conducted this study, whose objective is:

- To analyze how the nursing staff of a Pediatric and Neonatal Intensive Care Unit lives the death and dying of patients.

METHODOLOGY

It is a qualitative study, because it works with the nature of meanings, aspirations, desires, believes and values, we chose this path methodology that allows a better understanding of the perceptions of nursing staff before the experiences of death and dying.

The interviews were conducted in March 2012. The criteria for participation of the subjects were: to be a worker of the nursing team; to work in the NICU or pediatric and have experienced the process of death and dying of a newborn or child, and accept and have availability to participate in the research.

The space and time for the interviews were done as established in accordance with the Nurse Coordinator of the unit. With the workers, we scheduled a date and a time in advance and conducted interviews during the time interval of workers in a nursing room attached to the unit, allowing the privacy and maintain the confidentiality of the information.

For the construction of the information we used the open interview with a question: How is it for you to experience death and dying children and neonates hospitalized in an ICU PN? For those who agreed to participate in the study, it was made clear about the importance that the answers being reliable and we read the term of Consent. After reading and explained the doubts, the consent was signed by the investigator and the subject respondent, in duplicate, remaining one with the researcher and one with the interviewee.

The interviews were recorded in audio-tape and later transcribed integrally, eliminating language vices and analyzed by content analysis.⁵ For the safety and protection of the identity of the subjects, they were named as: (E1, E2 until E20).

The ethical guidelines were observed according to the rules established in Resolution 196/96 of the National Health Council,⁴ establishing parameters for research involving humans. The research project was approved by the Ethics Committee in Research of the Regional University of Northwest of Rio Grande do Sul-UNIJUI, research protocol under nº. 0183/2011 of 12/12/2011; approved by the rapporteur in 8th March, 2012.

RESULTS AND DISCUSSION

To address issues related to death, being of the "I" or of "other" is always difficult and at the same time, complex, because the word has always stigmatized by the feeling of loss of life, which presupposes experience, familiarity, affection, hostility and separation. At the same time, such a situation is conceived and realized as a result of a linear temporal process, beginning with the birth, growth, development, aging, and, finally, death. However, this process can be "crossed" and interrupted in any of these phases.

It's about the situations of death and dying that break with this "logic" built, we impose our vision and analysis. In this work we treat the process of death and dying RN and children, from the speech of nurses working in ICUs that care for patients in these age groups.

Study participants were all employees of the nursing staff who work in the Intensive Care Unit and Pediatric and Neonatal Care Unit of a General hospital type IV, from the Northwest Region of the State of Rio Grande do Sul.

At the unit operate 32 nursing professionals. Of these, five are 27 Nurses and Technicians are in nursing. We interviewed 20 professionals and four nurses and 16 technicians in Nursing. One of the nurses refused to participate in the interview; among nursing technicians two do not meet the predefined criteria, two were on sick leave, one on maternity leave; enjoyed two holidays during the collection period, and four did not accept participate.

The reading and analysis of the contents of the interviews emerged a category of analysis that deals with the performance of the nursing staff regarding the process of death and dying, and for purposes of discussion, we built three subcategories which deal sequentially: the feelings of workers nursing the loss of patients due to the links established with these long periods of hospitalization; feelings exacerbated when the unexpected loss of patients who previously had been evolving positively, and the relationships with our family of patients.

◆ Category 01 - The role of the nursing staff regarding the process of death and dying in a pediatric intensive care unit and neonatal

The work of professionals in the health field focuses the attention and care of the individual, family and community, healthy or suffering from health problems, however,

whatever the field of endeavor, is guided by the maintenance of life and the quality of life and , why not, the death of those under their care. In this context, live and experience the processes of death and dying for these professionals is part of their daily do. The way they face these situations may be different, however, never without consequences. For interpretation and discussion of representations of the subjects of the study, we built three subcategories of analysis, as follows:

• Subcategory 01 - Experiencing the death: the broken bond and sense of loss

By questioning the study subjects regarding their perceptions of the process of death and dying of a child hospitalized in the ICU, we found that most of them refer to feelings of "powerlessness, pain, guilt and sadness," especially when it comes to patients, to which were used all available technologies and still no progression to death. These representations can be seen in the speeches of the study subjects, as follows:

[...] impotence in the sense that the staff does everything for this child and cannot save it. (E2)

[...] I keep unhappy, I do not despair, but I experience, [...] time of loss [...] powerlessness. You know that you did everything and still did not produce a positive effect. (E4)

[...] manifests throughout our inability [...] feel very helpless. (E8)

The daily experience of nurses in the NICU/Pediatric is not enough to accept the death of a child, because feelings like guilt surfaced failure and denial of death.

Emotional overload, powerlessness, release from suffering, acceptance, trivialization, trauma, identification, vulnerability, affection, solidarity, love, affection, respect, empathy, anger, discontent, and difficulty of acceptance unprepared "are feelings that can emerge between workers loss when nursing a patient.⁶

For the author, it is necessary to build spaces for discussion and qualification of workers to meet the "losses" resulting frequent in patients who are admitted to an ICU and that the sentiments expressed by the subjects can be identified that these are not fully prepared to deal with this issue.⁷

[...] I feel very sad [...] is a sense of failure [...] all of you and the child does not evolve. (E18)

[...] It's a complicated issue [...] is a sense of failure, impotence, do everything [...] but we are not able to save them. (E20)

During the profession, nurses aim to save lives and prevent death from happening. By putting into practice the goals of academic and realize that these proposed objectives do not follow its natural course establishes a state of sadness and frustration at the child's death.⁸

In general, workers are not fully prepared to face situations of death and to establish defense mechanisms that mitigate his sufferings, being necessary to revise the curriculum of training courses and formation of discussion groups on the topic.⁶

The feelings and perceptions that arise in workers on the death of a patient who was under his care, are experienced more intensely, especially when there is formation of affective bond between caregiver and care. For this bond is established, it is usually necessary to living for periods of longer and that this is a business relationship and empathy, which involves exchanges of affection, responsibility, affection, care.

The ICU attending Premature Newborns with low birth weight and multiple complications, which may remain hospitalized for months, they offer the necessary conditions for the establishment of relations, in addition to technical and professional care, predisposing the team to get emotionally involved with the be careful. So when there is breaking the bond established with the patient, due to death, feelings arise, this situation is felt and experienced by practitioners as something that undermines their emotional state. The references about this can be evidenced in the words of the study subjects below:

[...] children in the pediatric ICU that you have created that bond [...] that bond affects you a little psychological [...] you have a connection with this child [...] this is a death that surely you will feel to come off saying goodbye is bad. (E3)

[...] Have children who come to us with 500g, 600g and when he sees are in 2kg, 2kg and little [...] and when you see this kid loses, we get very attached to it! (E1)

[...] The bond is not the same with that child who does not have a connection [...] the depth of this feeling [...] this sadness to experience this grief is not that different touch, but the deepen this feeling is different. (E4)

[...] We gets involved clinging [...] we suffer along well with parents. (E10)

Nursing often engages with hospitalized children, simply because they are children or your life path. But the involvement of this bond can cause immense pain and

psychological consequences for bringing this professional when the child goes to death.⁹

The difficulty facing death is when the bond that is formed during the care provided the child is broken by death. This experience reportedly make the process of death and dying more costly and painful because the worker engages with the child, creates bond and affinity making the process of shutdown bond that difficult to accept, affecting his mental state and the integrity of professional.¹⁰

At the same time, other employees of the nursing team, face the death of a child who was under his care, in a natural and even with a certain "coolness", comforting themselves with the feeling of accomplishment, that staff did everything they could while it was possible to fight. In the speeches of the study subjects can identify their interpretations on the subject.

[...] at the beginning it is more complicated I shook me more [...] just accepting that did everything for that patient helped in the best way possible. (E5)

[...] at the beginning it was very difficult [...] death [...] came home and cried, I felt really bad [...] the time now with [...] we realize that is a thing of life [...] but we know who did our part so there's no remorse resentment tried everything possible. (E19)

[...] We're sad, but it is something that happens naturally. (E17)

Death is often perceived, and the pain is alleviated when the human comfort in the sense of having done his role function. Over time this view just reassuring and providing comfort to professionals, however we know that not just the technical preparation - scientific to learn to face death, but the need to accept it as a natural process stressing that this acceptance does not happen from one moment to another, but rather to be built gradually in that people experience different stages of life.¹¹

From the speech of the study subjects is possible to notice that the mechanisms for some professionals, insofar as these learn to cope better with death, either by daily experience, or experience throughout the profession, experience with these processes most natural, yet not become desensitized to the point of not emote before death. But others are emotionally involved with the children and see the face of death emerge feelings of loss, grief, sadness and helplessness.

◆ Subcategory - 02: The favorable and unexpected death

Much of the professionals have difficulty facing the process of death and dying patients who are under their care, as these situations are forced to recognize that their goals were unsuccessful as professionals prepared to save lives.¹² However, as we saw in the discussion set forth in the preceding paragraphs, the ways in which workers face death of a child and a newborn depend among other things, how to interpret the death "thing of life" (E19), and the time operations in the area.

The death of the child in the PICU can be classified into two groups with the unexpected death happens by trauma or septic shock, for example those situations where death occurs even after using all available resources and technologies; the expected death in cases of chronic diseases, multiple organ failure, after many unsuccessful treatments. In some cases, after it identifies the table irreversible patient decides for therapeutic limitation.¹³

In the condition of expected death, sets up a period of hospitalization, convalescence and progression, slower or faster, to death, this timeline called "dying process". However, this period is never enough for awareness and preparation psycho workers to face the death of someone who in their care. However, the unexpected death is more difficult to overcome and is experienced and felt with frustration among workers, especially when it comes to situations where the child / RN is in an evolutionary process with positive prognosis and unexpectedly suffers some kind of injury leading to the death. These situations are referred to by workers of the nursing staff as being "unacceptable."

[...] For neonates [...] we see a good recovery that is evolving as well [...] and when you least expect it is a surprise, takes you by shock is also a thing we do not accept. (E3)

The team is emotionally shaken when a patient progresses rapidly to death and suffering, as a team and as a person when death happens after long days in the hospital, because they understand have dispensed great efforts in vain, for the result was unsatisfactory.¹⁴

The unexpected death disrupts the team and the family, because this kind of death does not follow the same course of illness and go through the process of dying. The death causes great uncertainty and becomes frightening for humans and is more complicated than the process of death and dying of a child who was hospitalized unexpected death scares, scares and hurts a lot.⁹

[...] Death [...] that you do not expect when suddenly you will see [...] hurts, we feel very sorry we do not wait, your call ends! (E1)

[...] When you get out what happens [...] you go out too devastated [...]! (E12)

Both the expected and the unexpected death you experience feelings of grief, fear, anxiety, powerlessness. The employee may be without knowing how to act against this situation, especially in the case of children and young people where the expectation is longevity. It is clear, however, that the expected death or the dying process is accepted more easily than the unexpected death.¹⁵ It is difficult to face and experience without getting emotionally involved, either death situations, however, the feelings are more intense and more evidently arise in situations of unexpected death.¹⁶

Clearly, regardless of how occurs, either expected or unexpected death of a patient is perceived by the employee as a loss surrounded by feelings of sadness, helplessness, guilt, and also of accomplishment. But when death happens unexpectedly these feelings manifest themselves exacerbated acutely reaching and impacting more on the emotional intensity of the professionals.

• Subcategory 03 - The professional before family

Monitor and be close to the patient in their families in times of death and dying is a function / action inherent to nursing professionals working in areas of health care, especially for those who work in ICUs. For the author it is the nurses do the "link" between the child and the family, welcoming them in a humane way.¹⁷

In particular, the ICU is a hospital where death is a constant, and the experiences are unique and singular cohabitation and this requires us to have a better understanding of this fact, so we suffer less and better help patients and their families.²

It is known that the admission of a child involves not only the patient but the entire family, more or less intense, engage with care. Provide support to the family of being interned is part of the process of nursing work and thus is dissociated from the process of taking care professional.

In the speech of the subjects of this study is that one of the greatest moments of tension and difficulty experienced by them is when the information is given to parents about the death of his son. In these moments, believe they participating in the "deconstruction" of life expectations created by parents and at these times it is necessary to support the family. On

the other hand and at the same time, they feel too vulnerable and how many workers have no psychological support to face this situation.

[...] Do not have a psychological sense that [...] is very complicated. (E14)

[...] The issue of parents is very difficult [...] you have a news of these [...] what you will talk to a parent at such a moment? What will comfort a parent? It has many moments that words fail. (E6)

[...] Harder newborn really is a dream ends there because of them that's there for you to solve, help you see yourself helpless because you can not help and give enough for them. (E7)

We also suffer because of the parents' suffering. (E9)

Importantly, in many circumstances the child's death cannot be avoided, but the team before this fact should provide support to the family in need of care and support to drive the best way this situation.¹⁸ A stressful situation is the routine work in the ICU, which implies living with the death of these children and the relationship with the family in times of suffering.¹⁴

[...] Have to be strong even to go to the parents, because employees can not get desperate and spend it for parents. (E11)

[...] It is very painful loss itself is painful [...] but the child weighs too much, if we put in place a lot of parents who are there with all hope they never lose hope in a son that here. (E15)

The author states that the nurses do not know how to approach the child's family in a state of death, but would like to know, would like the institution they work to offer them professional support before the death and consider necessary in academic preparation, preparation the unit in which they work and psychological support constant.¹⁹

Workers at ICU with something unexpected and, on the processes of death and dying, manifest different feelings making you realize, often without knowing what to do before the patients and their families, who often find is unhappy with the situation.²⁰

For the author it is of the utmost importance to welcome the family as an extension of the patient that this is about their care in the ICU or care units (Silva, Campos, Pereira). These in and often end up getting sick along with your loved one. So the families represent strong concern for the team in tackling this before death.²¹

[...] We're sad [...] I'm more sad for the family [...] because there are parents who are hoping for that child. (E13)

[...] When a child dies we feel we can not give everything we could have given [...] but we suffer with parents too. (E16)

The nursing staff often share feelings with family members of hospitalized patients and that

talking about death with the family still has constituted as a taboo, despite the need to leave the family aware of the conditions of his being and treatments to be followed. The author also refers to the importance of encouraging the family to talk about the process of death and dying for it to have a better elaboration of mourning. However, professionals have great difficulty communicating or inform the family about death a poor prognosis of their loved one, because, though it may be expected, the family is never fully prepared to accept the death of their loved one.²⁰

It stands out, so the death of a child produces feelings of pain in all families and professionals who were involved in the care process. It is crucial that in daily life and for coping with difficult situations such as the condition of death of a child, those professionals are emotionally prepared to face and live their own feelings and at the same time, support the family. But the lines that follow show that there is need for greater investment in the preparation of workers to cope with these situations:

For this process becomes less traumatic and emotionally costly for workers and family is important that the family is aware of health conditions and risks of its being found, as well as about the prognosis of the disease evolution.

At the same time, it is crucial that health institutions make available, steadily, psycho-emotional support and guidance to employees, as they live and coexist with the processes of death and dying in the ICU, and as mentioned in previous periods, is yes, nursing that 24 hours a day is close to the patient and family and it is who first realizes the imminent danger and death of hospitalized patients.

FINAL CONSIDERATIONS

This study showed the perception of the nursing staff regarding the process of death and dying in a Pediatric and Neonatal ICU, and allows us to infer that, even being part of the work of professionals, they perceive and experience different ways.

Feelings of helplessness, pain, guilt and sadness concerning the death of patients, are the most frequent references in the speeches of the study subjects. At the same time, the workers realize the "loss of the patient" with certain naturalness, comforting in the sense of duty, or to have made use of all the possibilities and technologies available in an attempt to avoid death. We rather as workers in the health field, the "hardening", enough for us to live and commune with the dead and dying children and infants as something

"natural", however, and as humans, we can never lose tenderness, sensitivity and ability to feel emotional and, why not, to mourn the death of a patient who was under our care.

The feelings touched upon before the death of a newborn child and are experienced more intensely by the workers in the greater length of stay of the patient in the ICU, as long as the interaction is bonding between caregiver and care and in such situations, workers suffering before death is exacerbated.

In case of unexpected death of the patient was improving and that more or less rapid will to death, feelings of frustration, sadness, helplessness are more present among the workers. In these cases, the relationship with the family also creates suffering for workers while they are weakened by the loss and need help; they need to support their families.

We believe rather that the way each subject and professional perceive and realize before the process of death and dying depends on how they perceive life. We also know that the fact of acting within an ICU and mingle with some frequency in situations of death and dying, is not sufficient for the worker to learn to cope with such situations, requiring major investments aimed at personal and institutional construction coping mechanisms that minimize the suffering of workers before the death of a newborn or child.

We believe that this work can help workers find their major gaps in addressing the face of death, a fact that must be dealt with professionals so that they live and to experience death as a natural process that happens to everyone regardless of which make life.

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